

END-OF-LIFE *Care*



Chapter 3

Pain and Other Physical Symptoms

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Pain Is Known Best by the Person Experiencing It



Quite simply, “pain is what the patient says hurts,” according to Dame Cicely Saunders, MD, founder of the modern hospice movement. In other words, pain is known best, and only, by those experiencing it. Pain can be relieved in most terminally ill patients, and managed for the rest. The cancer pain guidelines developed by the Agency for Healthcare Research and Quality, available at www.ahrq.gov, can be used for managing cancer pain as well as pain in other terminal illnesses. The guidelines include using opioids (narcotics) and other medications and include various medical treatments such as nerve blocks, surgery, radiation and chemotherapy. They also include complementary therapies such as massage, imagery and relaxation techniques. Support groups can be an additional source of comfort for terminally ill patients and their families.

Assessing Pain

For too long, too little attention has been paid to pain. Physicians and other health care professionals need to ask patients, especially those who are terminally ill, about their pain and level of comfort or discomfort. Continually reassessing a patient’s pain is crucial to successfully treating and effectively managing it.

New national standards developed in 2000 and 2001 by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) require health care facilities to:

- recognize the right of patients to appropriate assessment and management of pain
- identify pain in patients during their initial assessment and reassessments
- document acceptable outcomes of treatment
- educate providers, patients and their families about pain management

Several dimensions of pain must be evaluated when gaining an understanding of a patient’s pain experience. The most important is severity or intensity. Patients can use a 0-10 scale to rate the severity of their pain, with 0 being no pain and 10 the most severe pain imaginable. Scales that use pictures of faces can help children or those with a language barrier communicate the severity

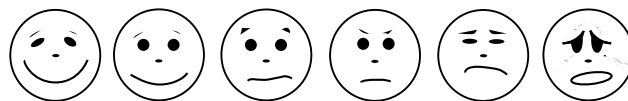
of pain. Pain scales also help evaluate success of pain treatment. Two examples are below.

Pain Scales

Numeric Pain Intensity Scale



Visual Analog Scale – Faces



Other Dimensions of Pain

In addition to the pain scales, ask your patients these questions to help assess their pain experience:

- Severity: Use pain scales.
- Quality: Is it dull, sharp, pressing, aching, burning, etc.?

- Location: Is it deep inside or close to the skin? Does it stay in one place or spread?
- Duration: When did it start? Has it changed or gotten worse? Is it steady or does it come and go? Is it better or worse at any time of the day or night?
- What brings it on? Makes it worse? Helps relieve it?
- Treatments: What has been used? How effective were those treatments? Were there side effects: nausea, itching, drowsiness?

Successful pain management requires evaluating and understanding the concept of “total pain,” as described by hospice pioneer Dame Cicely Saunders, MD. It requires evaluating the physical symptoms of pain, and then looking beyond them to the effects that pain has on the lives of people who experience it.

Successful pain management also requires knowing how each patient copes physically, psychologically and spiritually with his or her pain symptoms. Are emotional symptoms contributing to the individual’s pain? What about interpersonal problems? Is there spiritual or existential distress that needs attention? (See Chapter 7, “Emotions, Spirituality and the Task of Dying.”) Some of this information may be gained by simply asking direct questions, but some may require a more sophisticated assessment.

Understanding, acceptance and support by family members and the entire health care team are crucial to relieving and managing total pain.

Dimensions of total pain include:

- Physical pain: Medical intervention can help relieve physical pain.
- Emotional pain: Anxiety, fear, anger and depression are often part of the experience of pain. Medications may help, but addressing the emotions and their causes also is critical.
- Social pain: Social isolation, changes in relationships, tension and financial stress within families are sources of social pain.
- Spiritual pain: Not having made final peace with oneself, with others and with one’s faith can be a source of spiritual pain.

Many other medical interventions may be helpful for some patients, such as nerve blocks and radiation therapy. Physical therapy and occupational therapy may help with pain management and may also improve functional status.

Complementary therapies can play an important role in pain relief for many patients. Techniques like massage, relaxation, imagery, music and self-hypnosis can help relieve the stress and tension of terminal illness as well as assist with pain relief. People experiencing pain, along with their families, also may find comfort in support groups.

Addressing spiritual distress is another vitally important component of pain relief for many terminally ill patients. Strategies for understanding and addressing these concerns are discussed in Chapter 7, “Emotions, Spirituality and the Tasks of Dying.”

Pain Relief

Opioid (narcotic) medications are the cornerstone of pain relief for patients facing terminal illnesses. Unfortunately, many myths about opioid use have stood in the way of appropriate therapy. Non-narcotic medications also play an important role in pain relief, from non-steroidal anti-inflammatory drugs (NSAIDs) to adjuvant analgesics such as corticosteroids, anticonvulsants and antidepressants.

Barriers to Adequate Pain Management

Despite our current knowledge and treatments, pain too often is inadequately managed. Barriers to good pain management can arise from patients and their families, from health care professionals and from the health care system itself. Barriers to adequate pain management may include:

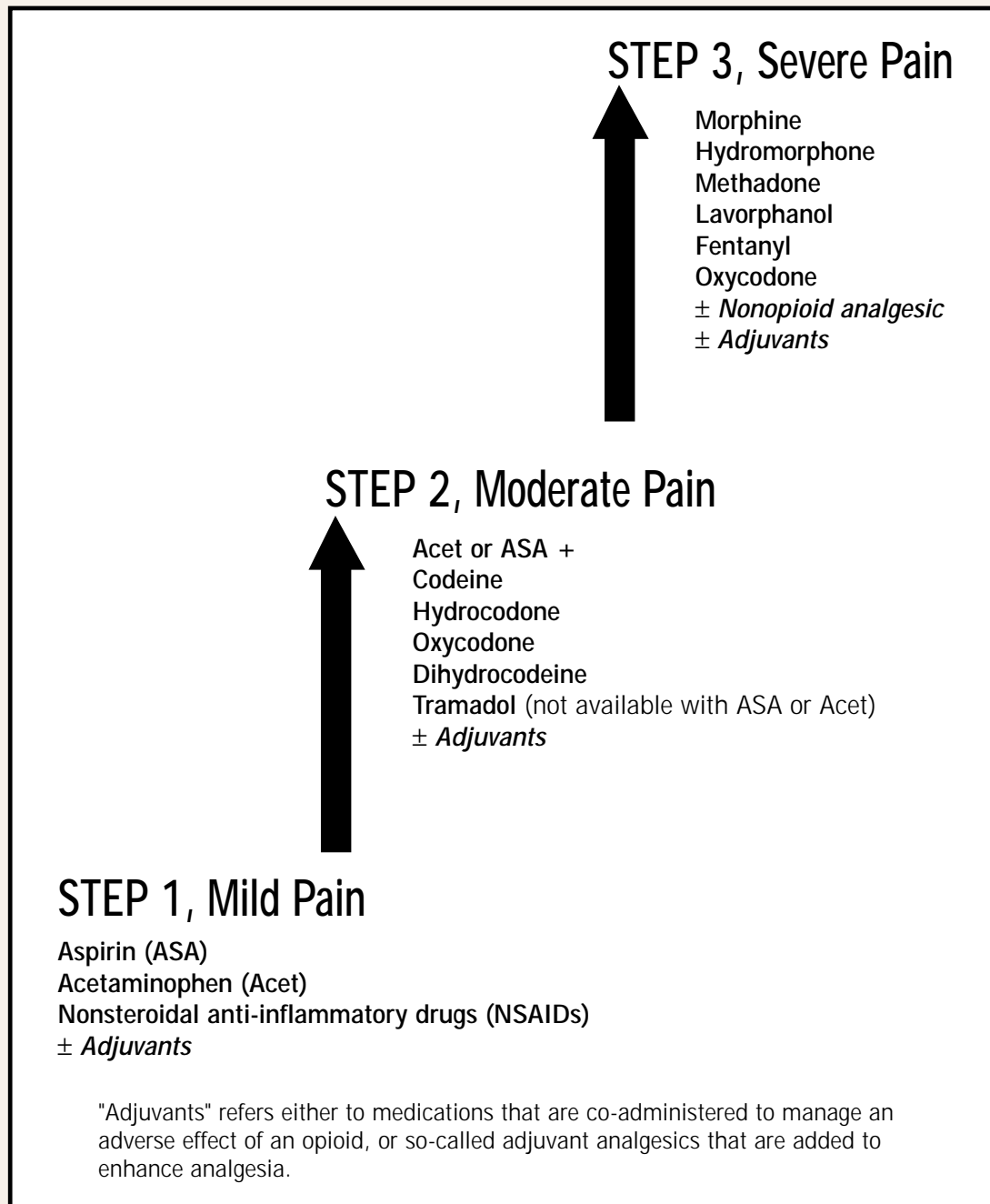
- Insufficient emphasis on the importance of pain management.
- Failure to assess the physical, emotional, social and spiritual causes of pain.
- Inadequate knowledge of effective pain management treatments.
- Irrational fear of addiction, tolerance and physical dependence.
- Physicians’ fear of governmental regulations related to prescribing opioids (narcotics).
- Inadequate insurance coverage or access to medical care for some patients and families.

In 1986, the World Health Organization (WHO) developed a three-step conceptual model to guide the management of cancer pain. It provides a simple, well-tested approach for the rational selection, administration and titration of analgesics. Today, there is worldwide

consensus favoring use of this model for the medical management of all pain associated with serious illness. The following chart is adapted from the WHO and Education for Physicians in End-of-life Care (EPEC) Project training materials.

Pharmacological Approaches to Pain Management

Adapted from the Education for Physicians in End-of-life Care (EPEC) Project's Version of the World Health Organization's Three-Step Ladder for Management of Pain.



Myths About the Use of Opioids (Narcotics) to Control Pain

MYTH: *Strong opioids (narcotics), such as morphine, should be used only when pain is unbearable or when death is near.*

FACT: If a patient's pain requires the use of strong opioids, they should be used immediately. In fact, this will help prevent changes to the nervous system that can make future pain more difficult to treat.

MYTH: *The use of opioids will hasten death.*

FACT: Appropriate use of opioid pain relievers does not shorten life. In fact, many experts agree that the physical stress of unrelieved pain may hasten death.

MYTH: *Strong opioids cause sedation and loss of function.*

FACT: Mild sedation may occur when opioids are first used, but with appropriate adjustments of dosage and schedule, most patients find they function very well—often better—than when in pain.

MYTH: *Strong opioids such as morphine can be provided only parenterally.*

FACT: Morphine and other opioids are very effective when taken orally. Fentanyl also may be administered transdermally, through a skin patch. These simpler routes of administration are usually less expensive, more convenient and just as effective.

MYTH: *Opioid use for pain relief causes drug addiction.*

FACT: True addiction (psychological dependence) is rare when opioids are used to relieve pain.

Many studies indicate less than one percent of patients with pain develop this problem from medical treatment. Physical dependence (withdrawal symptoms if medication is stopped abruptly) is common with sustained use of opioids and should be anticipated. It can be managed easily if the patient's opioid requirements decrease. Tolerance (need for increased dosage to maintain same effect) infrequently occurs. Need for increased dosage is more commonly due to disease progression. When tolerance does occur, opioids can simply be increased as needed.

MYTH: *Opioid medications should be used only when needed.*

FACT: Pain relievers are most effective when pain is kept under continuous control by scheduled doses. An as needed schedule (PRN) often leads to less effective relief and higher total use.

MYTH: *Side effects from opioids may prevent many patients from using them for pain relief.*

FACT: Side effects such as nausea and vomiting, constipation and sedation or confusion can be managed by skilled clinicians. Properly managed, side effects rarely interfere with a patient's ability to use opioids.

MYTH: *Opioid medications will relieve all pain.*

FACT: Certain types of pain, commonly bone and nerve pain, may not respond well to opioids. When a patient treated with opioids experiences persistent sedation without good pain relief, he or she may have opioid resistant pain. An expanded treatment plan that may include adjuvant analgesics will be needed.

For Help with Relieving Pain

Pain relief can significantly improve the quality of life for patients and their families. Most patients' pain can be managed with currently available medical knowledge and treatment. Physicians can acquire the knowledge and skills necessary to provide such relief fairly readily.

A physician who needs assistance in relieving pain in terminal illness should consider the following:

- Contact the Michigan Hospice and Palliative Care Organization, 1-800-536-6300, for a referral to a local hospice provider.
- Find a local physician who has attended an Education for Physicians in End-of-life Care (EPEC) Project training course listed on the Michigan State Medical Society web site at www.msms.org/endoflifecare, which also provides a list of board certified palliative medicine specialists, or call MSMS at 517-337-1351.
- Visit the Education for Physicians in End-of-life Care (EPEC) Project web site at www.epec.net.
- Attend an Education for Physicians in End-of-life Care (EPEC) Project training course sponsored by MSMS or Northwestern University. Call MSMS at 517-337-1351 for details.
- Check the resource section at the end of this chapter for additional materials including web sites.

Managing Symptoms Other Than Pain

Managing pain is often the main goal of physical care for patients at the end of life. Many patients, however, also suffer from other distressing physical symptoms that may be even more challenging to relieve than pain. A physician should assess these symptoms while keeping in mind the needs of the whole person.

In some cases, finding out the exact cause of a physical symptom may lead to better treatment. For many terminally ill patients, however, identifying the exact cause is not always necessary or helpful in deciding upon a treatment plan. Testing can be exhausting and burdensome for the patient and may be in conflict with the patient's personal goals at this important time of life. Fortunately, most physical symptoms can be managed effectively without knowing their exact cause.

Difficulty with Breathing

At the end of life, shortness of breath and difficulty with breathing can be very troublesome and frightening to patients and family members.

When breathing problems get worse, or new ones develop, a search should be made for causes such as heart failure, infection or fluid collection that may be improved with specific medical treatment.

Even when specific treatments cannot be identified or are not effective, relief can be provided in most cases. Opioids (narcotics) are very effective in treating breathlessness in most patients. Tranquilizers also may be considered, particularly for relief of anxiety associated with breathlessness. Oxygen may be helpful for some patients.

Comfort measures also should be considered, such as using a comfortable chair with support for sitting up, use of a dehumidifier or fan, subdued lighting and soothing music. Most important of all for many patients is comfort from the calming presence of family and friends.

Constipation

Patients who are approaching the end of life may become constipated more easily because of inactivity and decreased intake of fluid and fiber. Constipation also is an expected side effect from the use of opioids. Doctor Cicely Saunders often said, "The hand that writes the opioid prescription should write the laxative prescription."

The consequences of unmanaged constipation may include abdominal discomfort, nausea and vomiting, and an obstructed bowel. It is important to remember that constipation is much easier to prevent than to treat. Patients and families should be instructed to report signs of constipation as soon as any symptoms occur.

To the extent possible, encourage eating more bulk-producing foods and dietary fiber supplements. Encourage physical activity and drinking more fluids.

Many patients at the end of life, however, need more aggressive management. Regular use of stimulant or osmotic laxatives, along with stool softeners when needed, will manage most patients. Sometimes suppositories, enemas and manual removal are needed.

Nausea and Vomiting

At the end of life, many patients lose interest in eating. They also may become nauseated more easily and vomit more readily. These symptoms may have multiple underlying causes. Medications should be reviewed to see if they may be contributing to these distressing symptoms and then eliminated or changed, if possible.

Symptoms usually can be relieved with anti-nausea medications. Treatment should begin with medication aimed at the most likely cause, but a physician may need to try more than one medication to find what works best. See the separate list of other possibilities to help manage loss of appetite, nausea and vomiting.

Anorexia and Weight Loss

A patient's loss of appetite and weight loss sometimes can be more upsetting to families and friends than to the patient. It is difficult to watch a loved one waste away, especially since many cultures strongly associate so much meaning regarding love and nurturing to the act of feeding.

Many patients with terminal illness, however, have little or no interest in food. Forced feeding usually does not improve the course of an illness. Being forced to eat and drink, in fact, may create considerable distress, including nausea and abdominal pain. Patients with little appetite often greatly enjoy what they do want to eat, but in small amounts.

Fatigue and Weakness

It is natural for patients at the end of life to tire easily and have less energy. Patients should be evaluated for depression and other underlying causes. Medications for pain and anxiety also can contribute to fatigue, and adjustments to them may be helpful. The underlying role of the disease should be clarified to the patient and family.

Symptoms of fatigue and weakness are not easily treated with medications, but some patients may benefit from corticosteroids and psychostimulants. Promote energy conservation and give permission to rest.

Helping a Patient with Anorexia, Nausea and Vomiting

- Assess the level of symptom distress. Sometimes the patient is relatively comfortable, but the family is distressed. Assess the family's needs also.
- Address underlying causes including constipation, dehydration or electrolyte imbalances, infections in the mouth, anxiety and depression.
- Educate and support family caregivers. Help them understand the normal progression of the disease. Identify things they can do to help.
- Explore the emotional and psychological meaning of the patient's not eating.
- Offer his or her favorite foods.
- Use nutritional supplements if agreeable.
- Eliminate unnecessary dietary restrictions.
- Reduce portion sizes and make food look appetizing.
- Avoid disagreeable odors.
- Maintain a comfortable environment, including room temperature, lighting and noise level.

Cognitive Changes

Cognitive changes such as confusion, disorientation, irritability and agitation are common at the end of life and can be frightening to patients and family members. These symptoms often fluctuate and the cause(s) are not easily determined or treated. The treatment goal is to relieve distress as much for the family as for the patient.

Medications may cause cognitive changes or make them worse. An effort should be made to adjust them carefully in order to effectively manage other symptoms while reducing troublesome cognitive changes. Elderly patients are particularly vulnerable to this problem.

Agitation, confusion and anxiety can be treated with tranquilizing medications to help reduce symptoms. These symptoms also can be reduced by a family caregiver's reassuring presence and a calming environment. Attention to spiritual concerns also is important.

Pain and Symptom Management — Just One Aspect of Care

Good pain and symptom management at the end of life brings obvious relief and unquestioned benefits to a patient and family members. Additionally, relief of physical suffering allows tremendous opportunity for growth and personal development in the patient.

The relief of pain may allow a patient to bring any healing needed to relationships, to say goodbye, to reminisce and to put accomplishments, joys and sorrows in perspective. It may allow a patient to gain clarity and a sense of completion about his or her life. A physician who skillfully relieves physical distress plays a pivotal role in making these growth opportunities real for a dying patient.

Effective pain and symptom management is just one aspect of improving the quality of life for a dying patient. The next chapter looks at palliative care, caring for the whole person—mind, body and spirit.

Quotable

"Patients look to physicians as their primary resource during this very difficult time. Pain needs to be managed by all physicians, not just subspecialists. However, in those circumstances where pain is difficult to manage, pain management physicians offer special skills and advanced pain treatments. Unfortunately, most pain specialists feel that their services are under-utilized in cancer pain. We could definitely be of more help to patients with severe or poorly controlled pain."

— Dennis Dobritt, DO
Chief, Pain Management Center
Providence Hospital and Medical Center, Southfield

"High quality comprehensive care of all patients—including infants, children and adults—at the end of life involves the provision of pain management principles that are well established. We, as physicians, have enough medical power and knowledge to relieve all physical suffering. The ability to provide physical relief exists for all patients with safe, effective, reasonable agents. Combining pain management with psychological, interpersonal and spiritual modalities provides for overall well-being for the patient and their family."

— Jeanne G. Lewandowski, MD
Medical Director of Pediatrics
Bon Secours Cottage Health Services, Grosse Pointe

"Hospice professionals are trained in pain management and the myriad methods to control pain. As a physician, you don't have to know everything about pain management techniques to be of help to your suffering patients. It's important to realize that hospice professionals are trained in the latest pain management techniques and will work with you to control your patient's pain."

— Colleen Tallen, MD
Medical Director
Hospice of Michigan, Grand Rapids

Pain Management Resources

Web Sites

www.aacpi.org—American Alliance of Cancer Pain Initiatives—an alliance of providers, clergy, educators and government dedicated to promoting cancer pain relief nationwide by supporting the efforts of state and regional pain initiatives.

www.ahrq.gov—Agency for Healthcare Research and Quality—provides access to guidelines for managing cancer pain; similar to **www.guidelines.gov** listed below.

www.ampainsoc.org—The American Pain Society, (847) 375-4715—a multidisciplinary educational and scientific organization dedicated to serving people in pain.

www.cancernet.nci.nih.gov/—National Cancer Institute, 1-800-4CANCER—most recent cancer information from the National Cancer Institute.

www.epec.net—The Education for Physicians on End-of-life Care (EPEC) Project—is designed to educate physicians around the country on the essential clinical competencies in end-of-life care.

www.guidelines.gov—National Guidelines Clearinghouse—evidence-based clinical guidelines and related abstracts, summaries and comparison materials for health care professionals, sponsored by the Agency for Healthcare Research and Quality, in partnership with the American Medical Association and American Association of Health Plans. Includes the AHCPR Cancer Pain Guidelines.

www.msms.org/endoflifecare—Michigan State Medical Society—includes a list of EPEC-trained physicians and board certified palliative medicine specialists.

www.painandhealth.org—The Mayday Pain Project—is set up to be an index with links to other sites and resources.

www.painmed.org—American Academy of Pain

Medicine—provides information on quality care for patients suffering from pain.

www.who.int—World Health Organization—information sources, health topics, reports, governance.

Books/Articles

- Handbook for cancer pain management. Weissman DE, and Dahl JL. Wisconsin Cancer Pain Initiative: 1996.
- Oxford textbook of palliative medicine, 2nd ed. Doyle D., Hanks GWC, MacDonald N., eds. Oxford, England: Oxford University Press: 1998.
- Pain relief in advanced cancer. Livingston T. Churchill: 1994.
- Primer of palliative care. Storey P. Gainesville, FL: American Academy of Hospice and Palliative Medicine: 1996.
- “UNIPAC three: Assessment and management of pain in the terminally ill. Hospice/palliative care training for physicians: A self-study program.” Storey P., Knight CF. Gainesville, FL: American Academy of Hospice and Palliative Medicine: 1996.
- “UNIPAC four: Management of selected non-pain symptoms in the terminally ill. Hospice/palliative care training for physicians: A self-study program.” Storey P., Knight CF. Gainesville, FL: American Academy of Hospice and Palliative Medicine: 1996.

CD-ROMS

- “Easing Cancer Pain.” Karen S. Ogle, MD, Palliative Care Education and Research Program, Michigan State University. Contact the Michigan State Medical Society at (517) 337-1351 to obtain copies. Also see **www.easingcancerpain.msu.edu** for the full content.

End-of-Life Care: Communicating With Your Doctor

Help Your Doctor Understand Your Pain

To help your doctor better understand your pain and help you find relief, think about the following questions and be prepared to answer them for your doctor or nurse.

- How severe is the pain? Many doctors and nurses use a pain scale: they will ask you to rate your pain on a scale from 0 to 10, where 0 is no pain at all and 10 is the worst pain you can imagine.
- Where is the pain? Does it spread or travel to other parts of your body?
- When did the pain start? Has it gotten better or worse? Is the pain steady or does it come and go?
- What does the pain feel like? Is it sharp or stabbing? Dull and aching? Burning?
- What makes the pain better? What makes it worse?
- What pain medications have you tried in the past? How effective were they? Did they cause side effects or problems? Have you used any other treatments?
- How is the pain affecting your life now? Is the pain keeping you from doing the things you want to do? How are you coping emotionally with the pain? How is your family coping?

